

Regional Centre for Quality of Health Care

# **HANDBOOK**

Developing and Applying National Guidelines on Nutrition and HIV/AIDS

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### For copies of the Handbook contact:

RCQHC, c/o IPH Makerere P. O. Box 7072 Kampala, Uganda

Tel: 256-41-530888, 530321

Fax: 256-41-530876 E-mail: mail@rcqhc.org **Or download from:** 

www.RCQHC.org or www.fantaproject.org

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## **Nutrition and HIV/AIDS**

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#### The authors of this handbook are:

Robert Mwadime, Child Survival and Nutrition Advisor, Academy for Educational Development (AED)/Regional Centre for Quality of Health Care (RCQHC), Kampala, Uganda

Marlou Bijlsma, Consultant and Nutritionist, University of Zimbabwe, Harare, Zimbabwe

Tony Castleman, Food and Nutrition Program Officer, Food and Nutrition Technical Assistance (FANTA) Project, AED, Washington, DC, USA

Dorcas Lwanga, Nutritionist, Support for Analysis and Research in Africa (SARA) Project, AED, Washington, DC USA

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## **Acronyms**

HIV

ACC Administrative Committee on Coordination

ACP AIDS Control Program

AIDS Acquired Immune Deficiency Syndrome

ANC Antenatal Care ARV Anti-retroviral

DANIDA Danish Agency for Development Assistance
DFID Department for International Development

(formerly CRHCS)

ESARO East and Southern Africa Regional Office FANTA Food and Nutrition Technical Assistance FAO Food and Agriculture Organization

FAO Food and Agriculture Organization GTZ German Technical Assistance

HMIS Health Management Information System
IEC Information, Education and Communication
IMCI Integrated Management of Childhood Illness

Human Immunodeficiency Virus

M&E Monitoring and Evaluation

MOH Ministry of Health

MTCT Mother-to-Child Transmission of HIV
NGO Non-governmental Organisation
PLWHA People Living with HIV/AIDS

PMTCT Prevention of Mother-to-Child Transmission of HIV

RCOHC Regional Centre for Quality of Health Care

REDSO USAID Regional Economic Development Support Office for East and

Southern Africa

SARA Support for Analysis and Research in Africa Project SCN Subcommittee on Nutrition (of the United Nations)

TB Tuberculosis

TBA Traditional Birth Attendants
TIPS Trials of Improved Practices
TWG Technical Working Group

UGAN Uganda Action for Nutrition Society

UNAIDS United Nations AIDS

UNICEF United Nations Children's Fund

USAID United States Agency for International Development

VCT Voluntary Counselling and Testing

WFP World Food Program

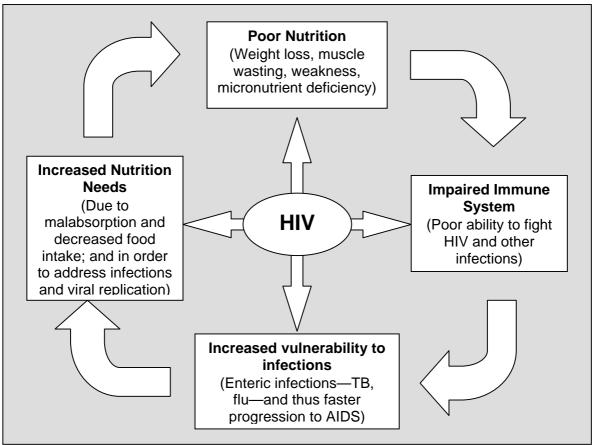
WHO World Health Organization

## **Chapter 1. Introduction**

## **Background**

Malnutrition and HIV/AIDS work in tandem, creating a vicious cycle (see Figure 1). HIV compromises the immune system of infected persons, increasing their susceptibility to other infections, which can negatively affect nutritional status. Conversely, malnutrition increases the severity of the HIV disease by further weakening the immune system, which decreases the body's ability to fight HIV and other infections.

Figure 1: The cycle of malnutrition and infection in the context of HIV/AIDS



(adapted from FANTA, 2001; Pediatric AIDS, RSA Nutrition/HIV guidelines, 2001)

HIV and resulting opportunistic infections can lead to deterioration in nutritional status by increasing the need for nutrients and energy and by reducing appetite and absorption of nutrients. The effects of HIV on a person's nutritional status can occur early in the course of the disease even when symptoms of the disease are not yet present.

Unless the cycle is broken, the overall effect is a spiralling deterioration of immune function and clinical status that contributes directly to repeated morbidity and the eventual early death of the infected individual. Timely improvement in nutrition can help strengthen the immune system, prevent weight loss, and delay disease progression.

Therefore, it is of paramount importance that people living with HIV/AIDS (PLWHA) have access to nutritional care and support. In order to maintain good nutritional status and help optimise immunity, nutritional deficiencies and loss of weight and lean body mass must be prevented or at least minimised. Evidence shows that some nutritional deficiencies can be reversed by timely and adequate nutritional therapy. Nutritional care and support for PLWHA can help manage HIV-related complications, promote response to medical treatment, delay disease progression, and increase the patient's quality of life by maintaining strength, comfort, level of functioning and dignity.

Service providers, programmers and caregivers may not have the necessary and up-to-date information and skills required to guide nutritional care and support for PLWHA. While many countries have guidelines for HIV/AIDS prevention and treatment, such guidelines often do not include nutritional care components. Nutrition guidelines that countries use generally do not fully address the specific needs of people living with HIV/AIDS. Current initiatives to provide nutritional care and support for PLWHA, such as those undertaken by NGOs and AIDS service organisations, are often limited in scope and coverage. Recommendations of different programs are often not harmonised with each

other.

The absence of national guidelines on nutritional care and support for PLWHA

The absence of national guidelines on nutritional care and support for PLWHA is recognised as a key limitation to the development and implementation of nutrition and HIV/AIDS interventions and strategies at all levels. National guidelines enable programs and services to provide consistent and sound

recommendations and they can contribute to greater awareness of the importance of nutritional responses to HIV/AIDS.

Most of the current technical recommendations for nutrition and HIV/AIDS are documented in two guides: the Food and Nutrition Technical Assistance (FANTA) Project's *HIV/AIDS: A Guide For Nutrition, Care and Support* (www.fantaproject.org), and FAO/WHO's *Living Well with HIV/AIDS: Nutritional care and support for people living with HIV/AIDS.* The content of these guides is appropriate for the majority of countries in the region. However, country-specific guidelines are often required to provide information relevant to the specific needs, issues, constraints, and food habits of individual countries. Technically sound and relevant national guidelines on nutritional care and support can be developed by adapting existing materials such as the above guides and by using experiences and resources available within the country.

This handbook does not provide comprehensive information about nutrition and HIV/AIDS. Rather, it provides guidance for the process of developing and applying national guidelines on nutrition and HIV/AIDS. For technical information on nutritional care and support, refer to the two documents mentioned above and to the resource materials listed at the end of this handbook.

## **Definition of guidelines**

The terms "policies" and "guidelines" are often used interchangeably. The confusion stems from the fact that the two processes are often inextricably linked, and in practice one should not exist without the other. The process of guideline development should be located within and informed by a conceptual policy framework.

Guidelines can exist at various levels. Common types of guidelines in the context of nutrition and HIV/AIDS are a) guidelines to inform system or policy elements, b) guidelines to inform service delivery and design, and c) guides to inform caregivers and PLWHA.

#### Guidelines to inform system or policy elements

In these guidelines, the key principles and positions that govern nutritional components in the comprehensive package of care and support for PLWHA are spelled out. In addition, the roles, relationships, and responsibilities of key stakeholders who will govern nutritional care and support are detailed. The key concerns about (in- or pre-service) training of service providers, materials production, supplies provision, and quality assurance are also addressed. This component can be included as a preamble or introductory section of the national guidelines on nutrition and HIV/AIDS or can serve as an attachment or alternatively can be a separate document.

### Guidelines to inform service delivery and design

These guidelines outline the elements (particularly evidence-based elements) crucial for developing or providing high quality, effective nutritional care and support. They define what the program/service providers need to do to care for and support PLWHA at various contact points (e.g., VCT, ANC, postpartum, agriculture extension, etc.) and for different target groups (e.g., pregnant and lactating women, young children, severely malnourished children, food insecure areas, etc.). National guidelines of this nature should accommodate the diversity of contexts existing in the country.

## Guides or communication materials to inform caregivers and PLWHA

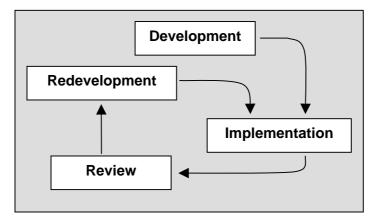
These are materials aimed at communicating key messages to caregivers and/or PLWHA. These guides provide information about service provision and key messages to use with general clients. To address local issues, concerns and specific needs, more detailed and specific operational guides may need to be developed at the programmatic or local level. These guides or materials are primarily written to communicate to caregivers and PLWHA and are composed mainly of key dietary messages (which may include recipes) for healthy eating and management of HIV-related complications.

As described in Chapter 2, an important step in developing national guidelines is to clearly identify the aim of the guidelines and the primary targeted audience. This will depend on the context in the country and assessed needs. Generally, focusing national guidelines to the level of service delivery and design is useful, though including concepts of the policy and communication levels helps broaden the guidelines' application.

In this context, national guidelines on nutrition and HIV/AIDS can be defined as fundamental tools used to assist service providers and service agencies (programs) to implement a specific service. The tools are drawn from current research (evidence-based), but placed within a social and programmatic context. Guidelines serve to assist decision-makers to develop and provide services, to harmonise service actions and messages, and to promote quality services.

### **Guideline development process**

Guideline development should be a dynamic, ongoing, and cyclical process. In order to serve as an effective guidance tool, guidelines should be produced through an ongoing process of development, implementation, review, and redevelopment.



**Figure 2: Guideline Development Process** 

## Objectives of the handbook

This handbook aims to support country-level working groups to develop and apply national guidelines on nutrition and HIV/AIDS. Therefore, this handbook:

- Outlines stages in the development of national guidelines on nutrition and HIV/AIDS;
- Provides suggestions for adapting existing materials, both generic and country-specific, to reflect country objectives for national guidelines;
- Offers recommendations for the application of the guidelines;

- Provides suggestions on monitoring and evaluating the development and application of the guidelines; and
- Suggests useful references and resource materials.

This handbook is written mainly for use by country teams mandated to develop national guidelines on nutritional care and support for PLWHA.

#### Structure of the handbook

"Development" and "application" of national guidelines are the key terms used in this handbook. Figure 3 shows the components of the process suggested in this handbook and the relation between these components. The handbook organises the process into distinct stages, but it is important to note that a) many of the stages occur simultaneously, b) some stages (such as consensus-building) need to occur throughout the process, and c) some of the later stages (such as application components) need to be considered early in the process.

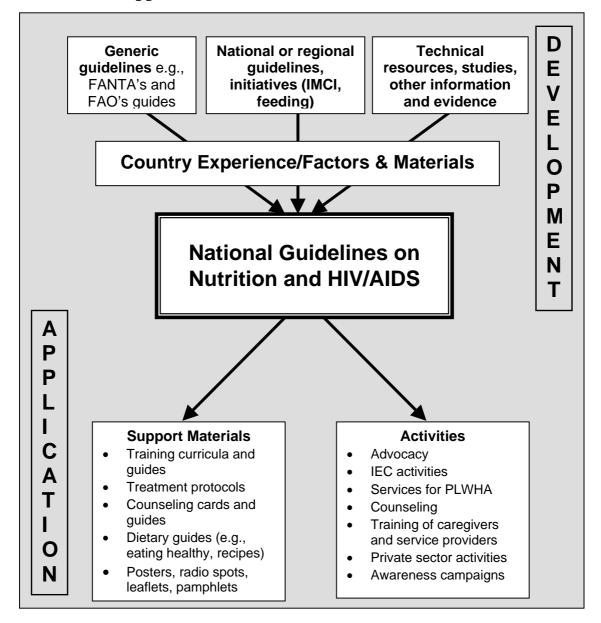
"Development of national guidelines" refers to the process leading to production of the guideline document. The process involves:

- Consensus-building and advocacy;
- Building a technical working team;
- Assessing the nutrition and HIV/AIDS situation in the country;
- Adapting existing guidelines and other technical materials on nutrition and HIV/AIDS to suit country-specific conditions and objectives; and
- Writing the guidelines.

Chapter 2 of this handbook outlines stages in this process of development. The chapter also refers users to sources of technical information that may be needed in developing guidelines.

The process emphasises involving all key stakeholders in order to build ownership and support for the process and final products. This stakeholder involvement leads to a more relevant and sound product and to greater adoption and use of the product by the various stakeholders. The final product of the process should be a document that is not only relevant and technically sound, but is also fully owned by the target audience.

Figure 3: Components of the Process of Development and Application of National Guidelines on Nutrition and HIV



"Application of national guidelines" refers to using the guidelines to strengthen nutritional care and support for PLWHA through programs, services, and other delivery points. The application process involves advocating for an enabling environment for nutritional care and support, strengthening services and other delivery points for implementation, and effectively communicating the guidelines' recommendations to the necessary target groups. This process is described in Chapter 3. Application also involves the production of relevant operational materials (such as client messages and dietary guides, counselling

aids, protocols, and training curricula) and the development of IEC activities and materials to be used at various contact points with PLWHA. Neither developing guidelines without effective application nor implementing nutritional care and support without proper guidelines will achieve the desired objectives. Development of national guidelines and their application must work in tandem.

Chapter 4 of this handbook provides suggestions on how to monitor and evaluate activities throughout the process of guideline development and application. Effective monitoring and evaluation helps to ensure that quality guidelines are produced and effectively used, provides information about results achieved, and informs future activities and improvements. The chapter discusses how to plan and develop a monitoring and evaluation system and offers examples of indicators to measure progress and outcomes for different stages of guideline development and application.

# Chapter 2. Development of National Guidelines on Nutrition and HIV/AIDS

This chapter suggests stages that countries can follow to develop national guidelines on nutrition and HIV/AIDS. Figure 4 presents these stages. Whereas some stages logically follow the previous ones, other stages will occur concurrently with others. The steps provided here are suggestions. Countries are encouraged to adapt, adopt, and adjust these stages as needed. Depending on the progress a country has made in the guideline development process and depending on the extent and relevance of existing background work, some of the stages laid out in this chapter could be omitted.

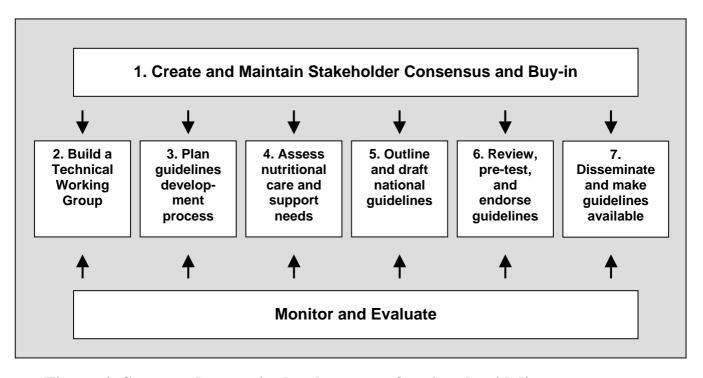


Figure 4: Suggested stages in development of national guidelines

As Figure 4 illustrates, the approach suggested in this handbook stresses the dominant role of continual stakeholder involvement to ensure consensus and buy-in throughout the process. It is also recommended to regularly assess progress against the planned activity schedule agreed to by the larger team of stakeholders.

The sections that follow address each stage in the development of national guidelines on nutrition and HIV/AIDS.

## Stage 1. Create and maintain stakeholder agreement and consensus

<u>Purpose</u>: To enable as many stakeholders and potential guideline users as possible to a) own the process and outputs and b) understand how the guidelines can support their programs and activities. A further purpose is to ensure production of high quality guidelines with input from multiple stakeholders.

### Why stakeholder consensus?

It is important to achieve a high level of consensus among key stakeholders on the process of development and application of the national guidelines for PLWHA.

Involving key sectors and stakeholders is necessary to ensure ownership and to ensure that the guidelines become truly national and are used in all the different relevant sectors and programs.

Achieving consensus may require frequent communication and advocacy with a wide group of stakeholders. The guideline development team will need to update stakeholders on the process and consult and negotiate with them on the content of the various outputs.

#### What issues need consensus?

Key issues on which to build consensus may include:

- The need to develop of national guidelines on nutrition and HIV/AIDS;
- The importance of a multi-sectoral and participatory approach;
- The purpose and use of the guidelines in addressing the nutrition problems of PLWHA in the country;
- The need for an environment that is conducive to nutritional care and support for PLWHA:
- The process of how to develop the guidelines;

- The existing and potential roles stakeholders can play in application of the proposed guidelines;
- The potential sources of resources for the development and for facilitation of the application of the guidelines; and
- Membership in the Technical Working Group (TWG) and selection of a team co-ordinator for the development of the national guidelines.

#### Who should be involved?

All key stakeholders should be involved in the process. Some may be active players in HIV/AIDS control and management, while others may be those working in related areas that are not yet directly involved in the care and support of PLWHA, i.e., potential actors. In contacting stakeholders and developing a team, consider if there are key actors whose buy-in is critical to the endorsement and adoption of the guidelines, i.e., political considerations. Also, look at the different steps in the process and identify who can help accomplish objectives at each stage.

Knowing whom to involve requires preparing an inventory of key programs, organizations and institutions that work with PLWHA, that support activities related to the care and support of PLWHA, or that have scope to include care and support activities.

#### These may include:

- People living with HIV/AIDS and their representatives: Make sure the representatives are those who can consult and collect feedback from other PLWHA regularly. Inclusion of a diverse group of PLWHA (e.g. rural and urban, male and female, adults and adolescents, and representatives from different professions and social classes) will help guidelines to reflect the varying needs and experiences of the different groups.
- NGO or civic sector: PLWHA organisations, organisations working in health, nutrition and food security, faith-based organisations, traditional healers, traditional leaders, unions, professional associations, NGO networks.
- Private sector: organised private sector coalitions for HIV/AIDS, workplace HIV/AIDS program managers, groups in regular contact with high prevalence populations (truck drivers, migrant labourers), businesses

significantly affected by HIV/AIDS such as agricultural companies and firms that rely on truck drivers.

- Public sector: Ministries of Finance, Health, Education, Agriculture, Mining, Community Development, Social Services, Youth and Sports, Uniformed Services, Information and Communications, Housing, Trade and Transport, Tourism/Hospitality, Justice and Human Rights.
- Relevant bilateral and multilateral agencies: USAID, UNICEF, UNAIDS, WFP, FAO, WHO, etc.

Example of a consensus-building meeting When the Uganda Action on Nutrition (UGAN) identified the need for national guidelines on nutrition and HIV/AIDS, they presented the idea to the AIDS Control Program in the Ministry of Health (ACP/ MOH). ACP/MOH then offered to support the process. UGAN and ACP/MOH supported participation in a Regional Workshop on Nutrition and HIV/AIDS. Immediately after the workshop a "partners meeting" was held. Thirty-two participants from the line ministries (health, agriculture, education. and community development), UNICEF, WHO, UNAIDS, WFP, FAO, Makerere University, Network of PLWHA, The Aids Support Organisation (TASO), AIDS Information Centre (AIC), etc. attended. The need for guidelines was reiterated and content and a potential process were discussed. ACP/MOH and UGAN were asked to solicit the funds for the effort and put together a technical team to start the process. Some participants volunteered participate in the technical team.

## How should consensus building be done?

Different methods can be used to build consensus; the appropriate method will depend on the target group and the desired outcome. Methods to consider include those in Table 1

**Table 1: Consensus Building Methods** 

Purpose	Method	Focus Issues
Consensus on the need for the guidelines and update on the process	<ul> <li>Meet and discuss the process and progress individually or in groups with relevant persons and programs.</li> <li>Make regular reports and distribute them to a wider group; circulate memos.</li> </ul>	Request participation and resources where necessary (human and/or financial).

Purpose	Method	Focus Issues
Consensus on the content and format	<ul> <li>Circulate drafts of guidelines, decisions on feeding recommendations, and local terms.</li> <li>Organise special meetings with relevant people to discuss particular technical issues.</li> </ul>	<ul> <li>Request comments and suggestions for improvements on these drafts.</li> <li>Identify emerging state-of-the-art information and research that need to inform the guidelines.</li> </ul>
Quality assurance of the outputs	<ul> <li>Involve local and external experts on specific issues as necessary.</li> <li>Involve technical resource groups such as FANTA, RCQHC and ECSA Secretariat to review draft guidelines (for technical quality)</li> </ul>	<ul> <li>Assess relevance, comprehensiveness , applicability, and technical soundness.</li> <li>Request information about possible gaps in the guidelines.</li> </ul>

The consensus-building process will often involve advocacy. For example, meeting with key stakeholders to build consensus on the need for, and uses of the guidelines also serves an advocacy role by helping build support among stakeholders for guideline development and adoption. Advocacy is discussed in greater detail in Chapter 3 because it is a key component of the application process.

## Stage 2. Build a national technical working group

<u>Purpose</u>: To put together a technical working group that is mandated and equipped to develop the guidelines.

## Whose responsibility is it to develop national guidelines?

This depends on the specific situation in each country. Most countries already have a body mandated to develop policies and guidelines on HIV/AIDS, e.g., a National AIDS Commission. Such a body may take overall responsibility for the process. In some cases, the process of developing and disseminating the

guidelines can be arranged by a government department or ministry or by a professional association such as a nutrition/dietetics association.

#### Who Takes the Lead?

In some countries, a nutrition society (such as a National Nutrition Coalition or National Dietetics Association) may take the lead to advocate for and facilitate the development of National Guidelines on Nutrition and HIV/AIDS.

Mandated institutions should take the

lead in developing the national guidelines on nutrition and HIV/AIDS. The mandated institution, in consultation with other stakeholders, may select the members of the technical working group (TWG), which then assumes day-to-day responsibility to facilitate the development and application of the national guidelines.

## What is the relation between the TWG and the larger stakeholder team?

Each country should use an arrangement that suits its context, but a general model involves having the larger group of stakeholders described in Stage 1 above identify the TWG, which will be a subset of the larger group. TWG members will then implement many of the specific activities, and a subset of the TWG would take responsibility to actually write the guidelines. The TWG will periodically update the larger group of stakeholders about progress.

#### Who should be in the TWG?

Given the nature and causes of malnutrition, a multi-sectoral and multi-

disciplinary approach to addressing nutritional problems in HIV/AIDS is essential. Professionals in nutrition related fields (public health nutritionists, dieticians, food technologists) and experts in HIV/AIDS.

communication/education, health care, and food security should be included in the TWG. PLWHA should be included in the TWG if possible.

## Characteristics of a team co-ordinator

- Possesses good rapport with various people and sectors.
- A strong advocate for issues of nutrition and HIV/AIDS.
- In a position to help build consensus across the technical members.
- Takes responsibility and is able to ensure that the process moves ahead and that products are of an acceptable quality.

A team co-ordinator should also be identified. This individual will play a key role in the team by facilitating and co-ordinating TWG activities and by representing the TWG to outside groups as needed.

#### Define the roles of the technical team members

Once team members are selected, their roles should be defined. This will help members to understand what work and outputs are expected of them and the extent of their involvement. At this stage, team members need to understand and agree upon the following:

- Each member's roles and responsibilities;
- To whom the team will be accountable (i.e., the larger group of stakeholders, the institution mandated to develop guidelines, or another body) and how this accountability will occur (reporting mechanism);
- How the TWG will operate and co-ordinate (communication mechanisms, meetings, etc.);
- The overall process, which requires discussion of the following issues:
  - o What are the actions needed to produce national guidelines?
  - What is the general outline and content of the proposed guidelines? Who is to write or compile the guidelines?

## Stage 3. Plan the guidelines development process

<u>Purpose</u>: To define what activities need to be done, develop an action plan, and budget the activities to be undertaken.

#### What needs to be done?

The technical working group needs to identify and plan the activities needed to develop the guidelines and to facilitate guideline application. Outputs from the various activities should also be identified.

#### Who will do what?

Identify individuals or institutions to carry out the stated activities. Orient them about the process if they are not part of the TWG. Sometimes this may involve

signing a contract or memorandum of understanding. For example, a National Nutrition Coalition, NGO, consultant, professional writer, or others who are not part of the TWG may be retained to perform specific parts of the process.

#### **Activities of the TWG may include:**

- Consensus-building throughout the process through stakeholder meetings, reports, etc.
- Mobilising resources for the process.
- Collecting locally available materials and accessing other technical resource materials.
- Assessing the needs of target groups and examining information about nutrition/dietary patterns of PLWHA.
- Adapting generic materials/recommen-dations
- Seeking external technical assistance as needed.
- Sending draft guidelines for internal and external review and incorporating comments.
- Pre-testing the guidelines (if needed).
- Editing, formatting and printing guide-lines.

#### Schedule the activities to be undertaken

The process of developing national guidelines may take a long time, depending on country-specific factors such as availability of key players, time required for funds mobilisation, the team-building process and the review process, and whether pre-testing is part of the process. Time required will vary from country to country, but approximately six to nine months can be expected.

In developing schedules and budgets, the TWG must allow enough time to conduct the key activities and take into account possible bottle-neck activities such as raising funds and reviewing drafts.

The TWG should also outline ideas and strategies for applying the guidelines. Activities related to guideline application (such as monitoring and evaluation) should also be scheduled.

The schedule of activities can be organised in an action plan. For each main step in the process, a well-organised plan lays out objectives, activities, parties responsible for conducting them, expected outputs, source of resources, and a timetable. Table 2 illustrates a simple action plan. Depending on context and

needs, a plan may require different steps in the process, a different sequence and timeline, or greater detail.

Table 2: Example of a Workplan/Action Plan for a National Guideline Development Process

Planned output	Activity	Who (responsible)	When
List of key stakeholders and contacts	Put together list of key stakeholder groups, contact persons within them, and maintain contact information	AIDS Control Program/MOH	Nov. 2001
Bibliography of nutrition/HIV/AIDS	Hire consultant to collect and give a brief synopsis of materials	UNICEF	Nov. 2001
materials being used in the	Review draft bibliography	TWG	Dec. 2001
country	Distribute bibliography to stakeholders. Obtain their feedback about possible additions.	TWG	Jan. 2002
Consensus on key issues by stakeholders	Hold workshop of key stakeholders	AIDS Control Program/MOH	Jan. 2002
Resources for development of guidelines	Prepare a funding proposal	TWG	Jan. 2002 (may be earlier)
	Contact potential donors	AIDS Control Program	Jan./Feb. 2002
Understanding of the needs that guidelines address	Conduct needs assessment of target group	TWG	Mar. 2002
Draft 1 of the guidelines	Appoint three technical people to draft the guidelines	AIDS Control Program	May/June 2002
TWG input and comments	Hold half-day workshop of TWG to review draft guidelines	TWG	July 2002
Reviewer feedback	Review draft guidelines by internal and external groups/individuals	AIDS Control Program	July 2002
	Incorporate comments	Consultant	Aug. 2002
Consensus on final content, format of guidelines	Hold one-day workshop to present draft guidelines to stakeholders	TWG	Aug. 2002
	Edit, format, and endorse guidelines	Consultant	Sept. 2002
5000 copies of national guidelines on nutrition/HIV	Print 5000 copies of the guidelines	TWG	Oct. 2002
	Launch guidelines in half-day meeting	AIDS Control Program	Dec. 2002
Dissemination of guidelines	Distribution through ministries, departments, NGOs, PLWHA networks	AIDS Control Program	Dec. 2002 - Jan. 2003
	District-level meetings and orientation		

The action plan and the associated budget may need to be discussed with the larger group of stakeholders. Benchmarks and indicators to monitor programs can be identified based on the action plan.

Where sufficient resources do not exist, the TWG, on behalf of the lead organisation, may need to prepare a funding proposal. Such a proposal can include the need/rationale for guideline development, steps in the planned activity, and the human and financial resources needed to carry out the specific tasks, such as meetings, advocacy activities, information collection, drafting guidelines, reviewing draft materials, field testing, expert consultation, editing, printing, and dissemination.

# Stage 4. Assess needs by gathering and analysing information on nutrition and HIV/AIDS

<u>Purpose</u>: To understand the country's needs on nutritional care and support of PLWHA and the sources of gaps in meeting these needs at policy, program, caregiver, and individual levels. To identify existing information and guidance on nutrition and HIV/AIDS and related subjects.

## What are the country's needs regarding nutritional care and support of PLWHA?

The content of the national guidelines should be guided by specific national information to the extent possible. The following questions will help guide an assessment of the country's needs and gaps in nutritional care and support of PLWHA.

- What approaches have been tried to improve PLWHA's nutritional status? Which approaches have been effective, which ineffective, and what have been the factors determining effectiveness?
- What nutrition services are being offered to PLWHA? By whom?
- How accessible are nutritional services to different groups of PLWHA?
- What is the content of the services? Is the content technically sound?
- What are the gaps—in policies, programs, service content, or communities—that prevent PLWHA from accessing nutritional care and support?

• What do extension/community-based service providers need (i.e., what additional information do they want)?

Understanding existing care and support approaches will help inform effective and usable guidelines. As much as possible, the guidelines should be viewed and placed in the context of the continuum of care and in a country's comprehensive care and support package for people living with HIV/AIDS.

#### What information needs to be collected?

The information to be collected for guideline development will depend on the objectives and target audience. Conversely, information collected will also inform the objectives by identifying where need exists.

The following general information may be needed:

- Information about PLWHA
- Priority nutrition problems for PLWHA (including food availability, access, taboos, dietary beliefs, etc.)
- Dietary patterns (the foods they have tried, the mode of preparation)
- Hygiene practices (including sanitation, safe water supply, knowledge and practices related to hygiene)
- Availability of basic equipment for refrigeration, cooking (fuel)
- Nutrition/dietary information needs for PLWHA
- Common medications being used, including modern, herbal and traditional therapies, their interactions with food and nutrition, and how to manage these interactions
- Review of existing broader guidelines, policies, and materials being used in the country to design and provide services on nutrition or on HIV/AIDS care.
- Review of technical recommendations or policy frameworks on breastfeeding in the context of HIV/AIDS and on nutritional needs—energy and protein and micronutrients—of PLWHA.
- Review of international guidance and other countries' guidance on HIV/AIDS nutritional care and support.
- Review of the coverage and quality of existing nutrition, health care, extension and counselling services and programs, and identification of gaps, such as:

- What information do service providers need to improve the quality of their services? In what format should this information be presented?
- What would programmers need to know to design and manage nutrition services for PLWHA?
- Identify strategies and indicators being used to monitor progress of nutrition and HIV/AIDS programs and activities.
- What information do trainers of service providers/researchers need?
- What is the supportive policy framework in the country?

#### What methods and tools can be used to collect information?

A number of methods can be used to collect the information needed to write guidelines. Existing, readily available information should be used as much as possible. For instance, routine health management information systems (HMIS), literature reviews, out/in-patient records, and program reports all can provide useful information. Below are some common methods of information collection and how they can be used for this process:

**Table 3: Methods of Information Collection** 

METHOD	HOW USED	
Reviews of international guidance on nutrition and HIV/AIDS, materials, records, reports, curricula, policies, standards, treatment protocols, job-aids, etc	<ul> <li>Identify what programs exist</li> <li>Survey content and coverage of programs and identify where gaps exist</li> <li>Assess content of related policies and guidelines</li> <li>Identify recommendations being made (e.g., on nutrient levels, foods, habits/behaviours)</li> </ul>	
Key informant interviews with PLWHA, health workers, counsellors, TBAs, care-givers, home-based caregivers, traditional healers, religious leaders, teachers, trainers, program managers	<ul> <li>What programs/services, foods, sanitation/hygiene, etc. currently exist?</li> <li>What are prevailing practices, eating habits?</li> <li>How are services (like counselling, VCT) used and what are the constraints to their use?</li> <li>What information (or other items) is needed to improve quality?</li> <li>How do needs and access to information and services differ among different groups of PLWHA</li> </ul>	

METHOD	HOW USED
Observation of services such as VCT, feeding of in-patients, care of severely malnourished children, recommendations in counselling sessions	Understand how the services and care are provided and what prevailing attitudes are
	Understand the content, quantity, and quality of services
	Where do gaps exist in content or coverage?
Observation of practices such as eating patterns in a household, food distribution, group education	Understand prevailing dietary habits (e.g., food eaten, frequency)
	Understand social networks and identify key targets for nutritional care and support
	Understand the different practices of different groups of PLWHA (women, men, adolescents/children, pregnant and lactating women, those taking medications)
Focus group discussions, with PLWHA, counsellors, care-givers	Discuss and understand nutritional/dietary needs of PLWHA, including variation between different groups of PLWHA
	Identify gaps in knowledge
	Assess information and attitudes on services being offered

No single method for data collection is comprehensive. Each method has advantages and limitations. Often a combination of several methods provides the best results. It is highly beneficial to include participatory methodologies as part of the process of assessing the nutrition situation and eliciting suggested ways to address problems.

#### **Share Experiences Between Countries**

Several countries in the East and southern Africa region are developing national guidelines on HIV/AIDS nutritional care and support. While some issues are country-specific, sharing information about the process and content can be very helpful. It may be useful for the TWG to be in touch with groups in other countries undergoing similar processes. For instance, South Africa, Uganda, and Zimbabwe may have lessons to share from their experiences. If needed, RCQHC can help put country teams in touch with each other.

## Analysis of information collected

The TWG's analysis of the information collected should inform design of the national guidelines. Depending on the level of information collected, analysis

may require substantial time and involvement from members of the TWG. Analysis of the information will equip the team to begin outlining and writing the guidelines document.

Focus analysis of the information on the following questions:

- 1. **Why** are we developing national guidelines?
- 2. **For whom** are we developing the guidelines?
- 3. **How** are the guidelines to be used?
- 4. **What** issues should be addressed and what information should be included in the guidelines?

### 1. Why are we developing national guidelines?

The purpose of developing the guidelines should be clearly stated. While the stakeholders may have defined this from the beginning, the gaps identified during the needs assessment stage will shed further light on what the guidelines should accomplish.

The purpose should be a broad statement that indicates the aim of the guidelines.

#### **Examples of Purpose Statements**

- To inform users about the correct technical information on nutrition in the care and support of PLWHA (*Uganda Draft Guidelines, June 2002*).
- To provide information and recommendations on nutrition and HIV/AIDS messages to communicate.
- To assist in the development of appropriate interventions and prevent commercial exploitation of PLWHA (Zimbabwe Draft Guidelines, May 2002).

Some guidelines specifically state "the objectives" of guidelines: i.e., what the guidelines are expected to achieve.

### 2. For whom are we developing the guidelines?

The target audience for the guidelines needs to be clearly defined. The guidelines will be more focused in content and format if the purpose and target audience are defined.

It might not be effective to target both health providers and PLWHA in the same document; this has been a limitation in some guidelines that try to target both audiences.

National guidelines are best targeted at:

- Policy makers (although a specific policy guideline may be even better for this group)
- Programs (e.g. home-based care, AIDS support organisations, VCT, ANC)
- Service providers (counsellors, health workers at various contact points, extension workers, teachers/trainers)

PLWHA and household-based caregivers are best reached by guides, IEC materials, and other materials that are based on the national guidelines, rather than directly by the guidelines document itself.

### 3. How are the guidelines to be used?

Based on information about existing services, expected users, needs, and gaps, the team should identify how the guidelines are expected to be used. The box below provides examples of potential uses. Guidelines can explicitly state some of the ways they are intended to be used.

The presentation of guideline content should be in a format that facilitates these uses and that allows different users to select the issues most relevant to their needs and to adapt the information to their situation and context. More details on presentation are given in Stage 5 below.

#### Potential uses of guidelines are to:

- Broaden advocacy: to raise awareness about the need for and benefits of nutritional responses to HIV/AIDS.
- Inform nutritional and dietary counseling and support development of the communication materials for this purpose.
- Enable integration of nutrition and HIV/AIDS interventions into PLWHA care and support, HIV/AIDS programming, and general health and nutrition services.
- Serve as a source for mass media and IEC messages that promote good nutrition.
- Advise on the content of service programs that support PLWHA or people affected by HIV/AIDS.
- Facilitate multi-sectoral integration of HIV/AIDS programming, such as integration of nutrition components into other HIV/AIDS programming.

## 4. What issues should be addressed and what information should be included in the guidelines?

The analysis should yield a list of the broad topics that need to be addressed in the guidelines document. The content should fill the information gaps identified, based on the intended objectives and planned uses of the guidelines.

With these topics, the TWG can develop a content outline covering the main topics to be covered in the guidelines. Members of the larger group of stakeholders should review the outline; different issues may be important to different stakeholders. Changes and additions to the outline should be made based on their input to ensure the content includes the topics that are pertinent to the different stakeholders.

Topics should be specific and comprehensive to meet the needs of the target audience. Examples of topics national guidelines may cover are shown in the Table 4.

This table is intended as an example. The content of a country's guidelines should be based on the specific needs and situation in the country. The topics listed above may not be comprehensive and they may include issues that are not needed in certain countries. For instance, in one country a stand-alone detailed topic on "Nutrition and Tuberculosis" may be necessary because it is an issue that the target audience requires information on; another country may decide to make "Food Safety" a stand-alone topic.

It is important to consult the wider group of stakeholders on the content outline before moving to the next stage of writing the guidelines.

**Table 4: Possible Topics in National Guidelines** 

ISSUE/TOPIC	CONTENT
Background information	<ul> <li>Magnitude of HIV/AIDS problem</li> <li>Rationale for guidelines</li> <li>Policy framework on which the guidelines are based (if any)</li> <li>Purpose/objectives of the guidelines</li> </ul>
Relationship between nutrition and HIV/AIDS	<ul> <li>Target audience</li> <li>The link between HIV/AIDS and nutrition</li> <li>Symptoms of HIV/AIDS that have nutritional implications</li> <li>Importance of proper nutrition for PLWHA (at various stages of the disease)</li> </ul>
Basic food/nutritional requirements for PLWHA	<ul> <li>Additional nutrient needs (macronutrients and micronutrients) for PLWHA</li> <li>Sources of food nutrients, nutrition value of local (including indigenous) foods</li> <li>Role of micronutrients and micronutrient supplements</li> </ul>
Information about positive living tips and their rationale	<ul> <li>Nutrition assessment of a person with HIV/AIDS</li> <li>Caring for a person with HIV/AIDS</li> <li>Food safety and hygiene (handling, storage)</li> </ul>
Nutritional/dietary management of HIV-related complications	<ul><li>Management of various symptoms</li><li>Use of herbs and traditional medicines</li></ul>
Nutritional care for children with HIV	<ul> <li>Nutritional assessment</li> <li>Increased nutrient/energy requirements</li> <li>(Special) Dietary management of food intake problems</li> </ul>
Nutrition of pregnant and lactating women with HIV	<ul> <li>Increased nutrient/energy needs</li> <li>ANC recommendations (i.e., iron supplements, workload, etc.)</li> </ul>
Infant feeding; prevention of mother-to-child transmission	<ul> <li>If guidelines on the subject exist in the country, it may be best to just refer to these in the guidelines or to WHO recommendations.</li> <li>Alternatively, guidelines can specify infant feeding and PMTCT recommendations.</li> </ul>
Nutrition and drugs	<ul> <li>PMTCT recommendations.</li> <li>Management of food and nutrition interactions with drugs, including ARVs, traditional therapies, and drugs for TB and other opportunistic infections.</li> </ul>

How to integrate recommendations for nutritional care and support in existing services	<ul> <li>Integration into various contacts and mechanisms in the health system</li> <li>Integration into home-based care</li> <li>Integration into VCT</li> <li>Integration into education/training</li> </ul>
Nutritional care in food insecure contexts	<ul><li>Backyard gardens</li><li>Food aid</li></ul>

## Stage 5. Write the national guidelines

<u>Purpose</u>: To write a technically sound document that is relevant (considering local, cultural, economic, food security, and resource issues) and in a format that is user-friendly to the target audience.

The guidelines should be based on the content outline agreed upon by all stakeholders. Again, it is critical to incorporate input from the wider group of stakeholders into the outline of the guidelines.

Those writing the guidelines should refer to generic guidelines, technical resources, available local materials, and other experiences needed to produce technically sound national guidelines. Two generic guidelines are recommended in this handbook: the FANTA and the FAO/WHO guides on nutrition and HIV/AIDS referred to earlier. These and other sources of information are listed in the resource materials section at the end of the handbook. Existing materials should be adapted to meet the country's needs and context.

Adaptation refers to integration of generic guidance and in-country materials, information, and experience to produce technically sound and country-relevant guidelines. In other words, for each issue/topic identified in the above outline, the writers identify technically correct information from existing materials. The information is put into the language, terms and format that best suits the target audience in the country. The resulting product should be consistent with the national policy framework related to the issue. Information should be presented in a format that can be easily used by the target audience with country-specific examples.

## Guideline content should be consistent with the policy framework in the country

Make sure no conflict exists between recommendations being made in the nutrition and HIV/AIDS guidelines and other existing guidelines or policies.

Important policies and guidelines that may need examination in developing nutrition and HIV/AIDS guidelines are:

- Treatment guidelines for the Integrated Management of Childhood Illness (IMCI),
- Antenatal care guidelines (or reproductive health guidelines)
- Guidelines to support PLWHA using food aid (if any exist)
- TB management guidelines
- Guidelines for home-based care of PLWHA
- PMTCT (and infant feeding) Guidelines
- National guidelines on voluntary counselling and testing
- Protocols for management of children with severe malnutrition

Given the rapid changes in nutrition and HIV/AIDS science, existing guidelines and policies may need periodic review.

#### Options for arrangements to write the guidelines

- Option 1) After agreeing on the target audience, objectives, outline, and general content, 2-3 members (or more) of the TWG guide the process of collecting the necessary materials and information and write the first draft.
- Option 2) Different members of the TWG write the different sections of the draft guidelines, according to their expertise. In such a scenario it might be necessary for one individual (or consultant) to integrate the sections and harmonize the language.
- Option 3) Using an outline and general content agreed upon by the larger TWG, a consultant or an NGO or firm is hired to collect the necessary information and draft the guidelines.

## The content should be relevant and technically sound

Content presented in the guidelines should address the needs and constraints of the country and should provide accurate technical guidance. Information and recommendations should:

- Cover the most serious and often recurring HIV-related complications.
- Address programs and contact points that are (or could potentially be) frequented by PLWHA or their caregivers.
- Be based on scientific evidence or on agreed international guidelines to the extent possible.

Given the scarcity of nutrition information in the context of HIV/AIDS, a tendency may exist to make recommendations based on intuition or personal experience. However, unless there is general agreement on the issue, it may not be wise to make such recommendations in national-level guidelines.

If unsure, consult with a) a wider scientific nutrition audience in your country, b) WHO, UNICEF, UNAIDS, FAO recommendations, c) the offices of these organisations in your country, or d) technical resources such as RCQHC or FANTA.

This may be particularly necessary for recommendations on food and nutrition issues related to alternative treatments and therapies.

# Guidelines should use language, format and examples that are appropriate to the country's context

#### For instance:

- The guidelines should recommend locally available foods or suggest substitutes that are affordable and culturally acceptable.
- Food recommendations should consider issues of seasonality in the availability of various food crops throughout the year.
- Recommendations should, where possible, use local terms for foods, illnesses and HIV-related complications, and medicines.
- If illustrations (e.g., of utensils) are being used, they should be locally familiar.

It may be necessary to consult local AIDS support organisations to understand some of the common terminologies.

### Information should be presented in a user-friendly format

Presentation of the content of national guidelines should be user-friendly to the targeted audience to enable effective application. Involving representatives from the various sectors and stakeholders throughout the guideline development process will support suitable presentation and ultimately enhance application. For example:

- In order to convey information in an understandable form, the authors should consider the guidelines' main target groups and look at the types of information commonly used by these groups.
- Guidelines should strike a balance between specific, comprehensive information and the need to develop a manageable document that covers all the agreed-upon topics.
- The use of tables, boxes, diagrams, question-and-answer sections, and pictures are possible user-friendly ways to organise and highlight information.
- Presentation should facilitate application of the content to communication materials. However, in order to be efficient and applicable to multiple sectors and different types of application, guidelines should focus on articulating and explaining the key information and recommendations, rather than on a particular type of communication material.
- National guidelines generally should not include many recipes or other implementation-level approaches. These can be included in materials developed based on the guidelines.
- Guidelines should be usable within the service delivery system.

## Translation into other languages

If a country is multilingual and different regions have different working languages, the team may consider translating the guidelines into multiple languages. This depends on who the main target groups are and whether they require translated guidelines in order to be able to use them. Cost considerations may also need to be considered. If necessary, the guidelines could be disseminated in one language and translated later based on assessed need and demand.

# Stage 6. Review, pre-test, and endorse the national guidelines

<u>Purpose</u>: To assess the soundness and applicability of the content and format of the proposed guidelines, and to obtain approval and support from the relevant body for nation-wide dissemination and adoption.

### Why review the guidelines?

The guidelines may need to be reviewed by both internal and external technical reviewers. Such a review process helps to ensure that the guidelines meet the expectations of different sectors and intended users, and also that the content is of high quality. Reviews help bestow the national guidelines with the credibility they require both within and outside the country.

### Who should review the guidelines?

The TWG should determine whether both in-country and international reviewers are needed. In-country reviewers are vital because they understand the local context and because the review process contributes to their ownership and support of the guidelines in their ongoing activities.

*In-country reviewers* could include the list of stakeholders developed earlier, such as:

- Key individuals living with HIV/AIDS (and/or related PLWHA support groups and organisations)
- Government ministries and departments such as health, nutrition, education, community development and agriculture, transport and trade
- NGOs, AIDS support organisations, and international organisations
- In-country offices of bilateral and multilateral agencies (like UNICEF, WHO, FAO, WFP, UNAIDS, USAID, GTZ, DFID, etc.)
- The private sector (large companies with HIV/AIDS care programs)
- Experts (or associations) in technical fields such dieticians, nutritionists, communication specialists, counsellors, HIV/AIDS experts, education specialists, as paediatricians, reproductive health experts, etc.

External review will primarily look at the technical content and ensure that recommendations are technically sound and consistent with the most up-to-date findings from HIV/AIDS and nutrition science. The TWG should identify external reviewers and provide clear terms of reference. Institutions such as RCQHC, FANTA, ECSA Secretariat, and UNICEF/ESARO can be approached to provide such reviews.

#### Why pre-test the draft guidelines?

Pre-testing helps in the process of adapting and modifying the guidelines to meet the needs of intended users. Pre-testing assesses the applicability of the guidelines; that is, how easily and effectively they can be used by the various target audiences, e.g., through counselling, curriculum development, training and material/message development.

#### How should the pre-testing be conducted?

The TWG should agree on the method, target audience, and length of time to pre-test the guidelines. Some options include:

- Presenting the guidelines to a number of institutions or individual users and asking them to apply the components of the guidelines that are applicable to them (over a defined period) before analysing the applicability. This option may require 2-3 months.
- Collecting observations on the service delivery (e.g., counselling sessions, training, IEC material development) from those who have been exposed to the guidelines. This option will also require time, but could be condensed into a shorter period than the first option.
- Holding a workshop for key representatives of the targeted audience to discuss the guidelines and how they would be used. This option may be optimal when time or financial resources are not adequate for a fuller pretesting process since it can be completed fairly quickly.

#### What aspects of the guidelines should be pre-tested?

The following aspects can be assessed during the pre-testing exercise:

- Do the guidelines meet the information needs of the target audience to enable them to make "informed decisions" in the care and support of PLWHA?
- Are the recommendations simple, clear and understandable for the target audience?
- Is the content technically sound? Are there any controversial recommendations?
- Is the content presented in a format that is easily usable/applicable?
- Are the recommendations feasible within the context and environment in which programs and service providers operate?

#### How should review and pre-testing results be used?

Feedback from the review and pre-testing exercises should be analyzed, and as necessary changes should be incorporated into the draft guidelines. For example, if parts of the guide are not clearly understood by key user groups, clarifications to these sections should be made. If reviewers identify relevant technical gaps in the content, additional information should be added to fill these gaps. Depending on the types of changes required, this may require substantial additional time, but it is generally a worthwhile investment to ensure that the final product is technically sound, relevant, and usable.

Since review and pre-testing activities can be expensive and time-consuming, these activities need to be planned and budgeted from the beginning.

After the national guidelines have been issued and applied, input and results from users can continue to be used to inform revision of future versions. Establishing a monitoring and evaluation system, described in greater detail in Chapter 4, can help to systematically collect and use information to enable the guidelines to be refined and improved in the future.

#### How should the national guidelines be endorsed?

Endorsement of the guidelines serves as a way to ensure commitment and support for their implementation. How to go about obtaining endorsement will depend on the circumstances in the specific country, such as who the optimal endorsers are and what "official" endorsement means. The TWG should identify what type of endorsement and by which officials will best ensure adoption and

spread of the guidelines. Two parts of an endorsement process are described below.

- 1. Consensus/agreement by and among stakeholders (including representatives of different groups of PLWHA). For instance, agreement that the guidelines provide information that serves their interests. While this is best done throughout the development process, a specific meeting or workshop to share the final guidelines and announce agreement may be useful.
- 2. Official endorsement by a senior government official and department. This gives the guidelines document the "approval" that shows it meets the government's standards and fits within the policy framework. This can be a critical step towards making the guidelines truly "national" and towards their wide adoption and use.

Once the guidelines are endorsed, they are ready to be printed, disseminated and applied.

#### Stage 7. Make guidelines available to the target audience

<u>Purpose</u>: To make the printed national guidelines available and accessible to the target audience.

The key issues in making guidelines available are:

- Having a strategy to print, store, and distribute enough copies of the guidelines.
- Ensuring the guidelines reach the appropriate institutions and people who need and can best use them.
- Orienting potential users on the use of the guidelines.

#### Who should get copies?

It is necessary to identify the different types of audiences to receive the national guidelines on nutrition and HIV/AIDS. To identify the various audiences, consider mapping the services available at national and sub-national levels.

Districts and provinces can help with the mapping exercise to improve the completeness of the list. The map may include a list of organisations or programs that provide or could provide care and support for PLWHA.

Most organisations providing services will include stakeholders involved in the process of preparing the guidelines, as identified in Stage 1 of this chapter.

### Who in these institutions should receive the copies and how many copies per institution?

While administrators or managers in the institutions should also receive copies of the guidelines, it is critical to ensure the guidelines are accessible to the individuals who directly implement activities. Different institutions will have different needs in terms of the number of copies required. For instance, organisations and agencies with widely distributed programs will require a greater number than more centralised institutions. Based on communication through stakeholder meetings, needs assessments, and pre-testing, the TWG should have an idea of how many copies different types of institutions require.

#### How many copies should be printed?

The number of copies of the national guidelines to be printed, at least initially, can be estimated by identifying the institutions and the number of individuals within the institutions who need individual copies.

### Factors that may determine the number of guidelines to be printed

- Demand by target groups
- Availability of resources
- Distribution/absorption capacity
- Storage space

Additional copies should be made for miscellaneous distributions to individuals or institutions, both locally and externally, and for future use.

Future printing should be guided by the demand for the guidelines. All the printing and distribution does not need to be done at the same time. Dissemination of the guidelines may need to be conducted in a phased process to match available resources and demand.

In planning the number to print initially, it should also be kept in mind that as new information emerges about nutrition and HIV/AIDS, guideline content would likely be revised for future printings.

### What mechanisms should be used to provide copies to the target audience?

The mechanisms and channels used to distribute the guidelines need to be carefully considered in order to ensure the guidelines reach and are accessible to the target audience. Distribution methods will depend on the size and geography of the country. Various options exist, including the following:

- Plan a national dissemination meeting and distribute the guidelines during the meeting, along with orientation.
- Plan district-level dissemination meetings that include distribution and orientation.
- Provide copies to sector teams at the sub-national level and request them to distribute them to all service providers—public and private—during supervision visits or district/regional planning meetings for all sectors.
- Distribute at upcoming annual health workers days or meetings at national or sub-national levels.
- Distribute with drug kits provided to all health facilities with a memo from the Minister of Health, Manager of the AIDS Control Program, or other authority.
- Use ministries' and departments' normal processes for dissemination of key materials and information.
- Distribute through medical, public health, and nutrition schools.
- Use National Health Days, National AIDS Days, and other events for distribution.

Sometimes a combination of methods can be used: for instance one could start by distributing the guidelines through the mail and follow up with an orientation about the guidelines at the sub-national level.

From the various options, the TWG should choose the most appropriate and cost-effective channels to reach the target audience and enable use of the guidelines. Different mechanisms may need to be used for different groups.

The following criteria may be used to identify mechanisms for dissemination:

- Should be cost-effective.
- Should make the guidelines readily accessible for use.
- Should be feasible and affordable with the available human and financial resources.
- Where possible, the process should be integrated with other information dissemination efforts (e.g., with support supervision, IEC distribution efforts, in-service training programs, etc.).
- Should be sensitive to stigma issues. Distribution methods should be acceptable to service providers and clients and not create increased stigma or discrimination.

#### What form of orientation should accompany the guidelines?

As indicated earlier, service providers should be able to translate the guideline recommendations to actions within their routine, ongoing services. The TWG may want to recommend an orientation package that includes updates on any new information and competencies (e.g., counselling) that may be needed. Orientation should focus on communication of guideline information and on integration of nutritional care and support interventions into the relevant services. Orientation may also cover the key technical messages and recommendations from the guidelines.

Various methods could be used to orient service providers. For instance, institutions may plan interactive sessions during appropriate times of the day to communicate the content of the guidelines and how service providers can integrate them into their ongoing work.

Orientation modules should be concise, user-friendly, and focused on the guidelines' key information, use, and implications for specific types of service provision. Job aids or protocols could be developed to summarise the key points of the guidelines.

Service providers can also be reached through support supervision, or by supervisors who can train others in the content of the guidelines—training of trainers. Introducing students of pre-service training institutions to nutrition and HIV/AIDS through workshops or training modules can be an effective method

to train new service providers. This process can be used to familiarise service providers with the guidelines, national policies, job aids, and other materials used in the implementation of services.

The existence of the guidelines and a summary of their content and purpose can also be published in a local newspaper or in magazines or newsletters that reach members of the target audience. This published statement should also specify where and how copies of the guidelines can be obtained.

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# Chapter 3. Application of National Guidelines on Nutrition and HIV/AIDS

#### Introduction

Access to national guidelines by potential users is critical, but access alone does not ensure that the guidelines will be effectively used to improve nutritional care and support. A number of factors can prevent effective use. The environment at the policy, program, and community level may not be conducive to application of nutritional care and support. Programs, services, and service providers may not have the capacity to integrate the guidelines into ongoing activities. Effective communication mechanisms and tools may not exist to translate the guidelines into practice.

This chapter discusses how national guidelines on nutrition and HIV/AIDS can be integrated into existing strategies for care and support of PLWHA. The process involves facilitating the target audience (service providers, programmers, policy makers, etc.) to use and communicate guideline recommendations and to mobilise additional partners to support essential HIV/AIDS care. One way to begin the process is to develop a strategy for using the guidelines, or an application plan.

How and to what extent the TWG will be involved in facilitating implementation of the guidelines will vary from country to country. For some, following the development of the national guidelines, the TWG may want (or be mandated from the beginning) to facilitate guideline application or to raise resources for application. In other situations, each sector may prepare and implement its own application plan.

The following sections describe three key issues that are critical to the process of applying national guidelines:

1. **Advocacy.** Undertake advocacy at all levels (policy, program, service provider, community, and individual) to ensure that the guidelines are acceptable and are used, that investments are made for nutritional care and

- support activities, and that an environment exists in which nutritional care and support can be effectively implemented.
- 2. **Services.** Support and strengthen service providers and other delivery points in the use of the national guidelines. Mobilise multi-sectoral and private sector partners to provide nutritional care and support services.
- 3. **Communication.** Identify channels and develop mechanisms and materials to communicate nutritional care and support messages to PLWHA and caregivers.

For each of these issues, the enabling and limiting factors should be identified and addressed.

# 1. Advocate<sup>1</sup> to create an enabling environment for use of the guidelines

<u>Purpose</u>: To identify and advocate actions needed to create an environment conducive to guidelines application.

### What actions are needed to create an enabling environment for nutritional care and support?

Incorporating national guidelines into existing services requires creating an environment supportive of nutritional interventions for PLWHA. This can be done through the following actions:

- Review and update other related policies and guidelines in order to create a framework that defines:
  - o government commitment to comprehensive care for PLWHA that includes nutrition,
  - o responsibilities in terms of leadership, co-ordination, monitoring and evaluation of nutrition related activities.
  - o sources of human and financial resources needed for nutritional care and support.
- Revise in-service and pre-service training curricula to include PLWHA nutritional care and support for all relevant cadres, such as nurses, clinicians,

<sup>&</sup>lt;sup>1</sup> In the context of this handbook, advocacy is not limited to influencing policies and strategies. Advocacy is used here to mean efforts to improve environments at the policy, program, service, and community levels for nutritional care and support.

medical doctors, nutritionists, dieticians, counsellors, home care providers, agricultural extension workers, community development workers, etc. Updated training curricula will support application of the guidelines in the future.

- Update and adjust administrative, informational and documentation tools that are necessary to enable service providers to include nutritional care and support for PLWHA in their daily routines. These include:
  - o job descriptions
  - o recording forms (e.g., HMIS, counselling forms)
  - o supervision schedules
  - o counselling guides
  - o treatment protocols
  - o home care protocols
  - o job aids, etc.
- Ensure multi-sectoral collaboration among different government, private and non-governmental institutions. The multi-stakeholder process and consensus-building meetings can support this.
- **Train service providers** who deliver services at the various contact points in which nutritional care and support is to be integrated.
- Orient communities and community organisations in the importance and benefits of nutritional care and support for PLWHA.

#### Why should we advocate?

It is important to ensure that there is awareness at all levels about the relevance of nutrition-HIV issues and the existence of national guidelines for nutrition and HIV/AIDS. Policy makers, service providers, and PLWHA groups should understand that the national guidelines specify requirements for quality nutritional care. There is need to ensure support at all levels for improving the quality of care for PLWHA, and recognition of PLWHA's right to nutritional care and support at all times.

#### What should we advocate at what levels?

The advocacy needed depends on the gaps identified—in part through the earlier needs assessment (Stage 4 in Chapter 2)—in the enabling environment for nutritional care and support for PLWHA.

Different types of advocacy are needed at the various levels where decisions about care and support are made: the national level (policy and political level), the programmatic level (including the private sector), and the community level. At each of these levels, advocacy should be conducted with the different sectors and types of stakeholders (government, NGOs, private sector, ASO, PLWHA, etc.).

Possible advocacy content and objectives are listed below.

#### At the **national level**, advocacy is needed to:

- Increase understanding about the need to integrate nutritional care into the package for comprehensive care and support of PLWHA and about mechanisms to do this.
- Increase awareness among policy makers in various sectors about the role of national nutrition guidelines in providing quality care for PLWHA (such as to slow progression of the disease and to mitigate its effects).
- Adjust the HIV/AIDS policy framework where necessary (including food and nutrition, HIV/AIDS, PMTCT, etc.) to incorporate guideline content.
- Develop new strategies and interventions to nutritionally support and care for people living with or affected by HIV/AIDS.
- Enhance multi-sectoral co-ordination to enable application of nutrition guidelines in a broad range of venues and services with access to PLWHA.
- Increase allocation of resources for dissemination and use of guidelines and for implementation of nutritional care and support.

#### At the **programmatic level**, advocacy is needed to:

- Develop new plans for nutritional care and support, including designing activities and setting targets and goals.
- Develop new services and materials for nutritional care and support for PLWHA where necessary.

- Integrate nutritional care and HIV into pre-service and in-service training curricula.
- Increase documentation of "better practices" in the nutritional care and support of PLWHA.
- Increase resources (financial and human) within existing related services (health, nutrition, agriculture, trade, education counselling, etc) to enable quality nutritional care and support for PLWHA.
- Review and update related materials so as to integrate nutrition care and support of PLWHA into other relevant guidance.

At the **community level**, advocacy and mobilisation are needed to:

- Provide an environment that enables behaviour change.
- Generate awareness among community members about the key nutritional care and support messages (such as increased energy and protein needs, reduced workloads for pregnant women, need for improved hygiene and sanitation conditions at household and community levels, etc.).
- Increase community and family support to follow recommendations suggested in the guidelines (such as increasing access to nutritious foods, meal and diet planning, immediate seeking of medical care for opportunistic infections that can affect food intake, etc.).
- Reduce stigma issues associated with HIV/AIDS that could deter implementation of the guidelines.

#### Advocacy methods

A range of methods can be used to advocate for nutritional care and support, depending on the objective, target audience, and desired end results. In some situations, a combination of methods may prove to be most effective.

Some advocacy methods that can be used to improve the environment for nutritional care and support include:

- Participation in strategic planning sessions and policy meetings
- Legislative lobbying
- Documentation and dissemination of successful results
- Individual testimonials, especially by PLWHA and family members
- Public statements by well-known figures, leaders, role models

- Statements by respected experts
- Meetings
- Educational talks
- Use of the mass media: newspaper articles, letters, advertisements; radio clips and interviews; television clips and interviews
- Demonstrations for educational, training, or health care institutions
- One-on-one discussions with key decision makers and stakeholder representatives
- Workshops
- Everyday communication with colleagues, friends, family, and acquaintances
- Group discussions on stigma and other issues
- Facilitation of communication between disparate stakeholders
- Audio-visual presentations—at government events, in communities, or for program decision-makers and service providers

While these are special advocacy activities, TWG members and other members of the larger stakeholder group can perform critical advocacy through their ongoing work within their ministries, organisations, etc. This is a key form of advocacy and part of the rationale for having a strong, broad-based team.

Whichever method is used to advocate or create consensus on the application of guidelines, it will involve gathering background information, understanding the gaps, understanding the motivations and needs of the audience being approached, and suggesting specific actions that are feasible and acceptable to the target audience.

# 2. Support services and delivery points that will use the national guidelines

<u>Purpose</u>: To facilitate the use of the guidelines by programs, service providers, and other delivery points.

#### How can the national guidelines be used?

National guidelines on nutrition and HIV/AIDS can be applied in a wide variety of ways. Figure 5 illustrates some of these uses. Often, a combination or

convergence of actions is most effective in bringing about behaviour change. For instance, IEC materials are developed within the context of IEC activities, which may relate to nutrition education courses or to counselling packages. Hence, utilising a number of types of activities together to apply the guidelines may generate the best results.

Develop counselling packages Develop IEC Design nutrition materials education tools **National** Develop Guidelines Design treatment curricula on can be used protocols nutrition/HIV to: Design activities of Plan IEC support groups activities Develop homebased care packages

Figure 5: Uses of National Guidelines on Nutrition and HIV/AIDS

#### Identify the services and delivery points that can use the guidelines

A variety of services and activities involve occasional, periodic, or sustained contact with PLWHA and caregivers. These offer opportunities to communicate nutritional care and support messages and to support their implementation. Integration of nutritional interventions often enhances existing HIV/AIDS services. For instance, improving the care for PLWHA may encourage people who are unaware of their HIV status to go to VCT centres. Therefore,

nutritional care and support can complement and support VCT and prevention efforts, as well as standard care and support efforts.

In addition to HIV/AIDS and health and nutrition programs, other delivery

points should also be explored, such as private companies' HIV/AIDS campaigns aimed at employees, education and agriculture programs, tourism and hospitality services, and private sector awareness efforts related to food and nutrition.

#### **Document Better Practices**

Support the replication and scale-up of successful programs and interventions. Identify and document "better practices" that emerge and share these with others. Use information about effective nutritional care and support approaches to review and update national guidelines, to inform recommended applications, and to develop local support materials.

The following strategies may be useful in identifying and supporting service delivery points to provide nutritional care and support to PLWHA:

- Include nutrition and HIV/AIDS in existing nutrition and dietary services.
- Integrate nutrition and HIV/AIDS actions suggested in the guidelines into existing HIV/AIDS care and support services.
- Provide up-to-date information and recommended approaches to improve existing nutrition and HIV/AIDS programs and services.
- Investigate and facilitate initiation of new services to address nutrition and HIV where needed.
- Integrate nutrition and HIV/AIDS into other non-health services that have strong access to PLWHA (e.g., agriculture, education, private sector, etc.).

## Integrate nutritional care and support activities into HIV/AIDS, health, and nutrition services

Recommendations from the guidelines can be incorporated into HIV/AIDS or other health and nutrition activities to support a comprehensive HIV/AIDS care approach. Possible methods to include nutrition and HIV/AIDS considerations from the guidelines into ongoing activities are listed below.

#### Voluntary counselling and testing

- Include a decline in nutritional status as a criterion for referral of cases for voluntary HIV counselling and testing.
- Create awareness and educate clients on the importance of nutrition and diet during post-test counselling to improve and maintain good nutritional status as soon as possible.

#### Clinical management

- Monitor nutritional status during clinical assessment and address declines in nutritional status as per the guidelines.
- Promote and carry out prompt diagnosis and appropriate treatment of infections to reduce the nutritional implications of the infection.
- Include nutritional management of HIV-related complications in clinical treatment practices and protocols.
- Provide appropriate diets to HIV-positive in-patients.
- Highlight and address implications of medications on food intake and absorption and vice versa, and offer recommendations for the management of these interactions.
- Provide recommendations to improve nutritional status following recovery from infection.

#### Nutrition counselling and education

- Provide nutrition counselling and dietary advice for PLWHA through various relevant channels.
- Provide education on nutritional care and support for caregivers, home care providers, PLWHA, etc.
- Provide practical training on nutritional care and management of HIV-related complications.

#### Social support

• Provide nutritional care and support information in social support services, PLWHA organisations, and NGO programs.

#### Home-based care

- Educate and provide skills training on home-based nutritional care and support to PLWHA and their caregivers.
- Train health care workers providing home-based care to include the nutritional management of HIV-related complications.
- Strengthen community support structures for nutritional care and support of PLWHA.
- Address the food security issues of needy clients and their families. Help
  them to optimise nutritional intake within their food security constraints,
  with particular focus on the special nutritional needs of PLWHA. If possible,
  provide referrals and linkages to programs and services that help improve
  household access to food.

#### Referral and networking

- Active referral of all PLWHA to relevant HIV/AIDS care and support services, including to social support services and NGO programs that provide nutritional care and support.
- Develop a resource pool of local trainers and facilitators equipped with skills and knowledge in nutritional care and support.

#### Integrate nutritional care and support into other delivery points

Non-health services should also integrate nutritional care and support, for example, through teacher training or orientation of agricultural extensionists working in high-prevalence areas. Key nutrition and HIV/AIDS messages can also be a component in mass media campaigns, private sector HIV/AIDS efforts for employees, and campaigns by food-related firms or professional associations. Involvement of stakeholders from these fields and sectors in the guidelines process will facilitate stronger application of the guidelines in these areas.

### Strengthen the capacity of service providers to incorporate nutrition and HIV/AIDS

A precondition for successful use of the national guidelines is the presence of institutions, programs, and service providers with the capacity to translate the content of the guidelines into practice.

The team may need to carry out a capacity analysis of programs and services to identify gaps in capacity at various levels. The following capacities are key:

- Adequacy of staff (service providers) in terms of numbers (related to workload), knowledge, and skills;
- Availability (timeliness and quantity) of essential supplies;
- Decision-making, leadership, and supervision; and
- Creating a suitable space and environment for counselling.

Table 5 indicates possible gaps that may exist in capacity, and recommendations for capacity development to address these gaps.

#### Train program and service personnel

Targeted training programs help to enhance human capacity at specific identified levels that require strengthening. The nutritional care and support messages in the guidelines are likely to be new for many program planners and service providers. Training helps them to effectively and accurately incorporate nutrition and HIV/AIDS into their activities.

Instead of separate special training processes for nutritional care and support, it may be more efficient and cost-effective to incorporate nutrition and HIV/AIDS components into existing training structures. Most programs and services have mechanisms in place for regular training, so rather than set up a parallel structure, it may be most effective to integrate guideline messages into these mechanisms.

For training to be effective, it is important to clearly identify which capacities the training aims to strengthen among which target groups.

Training can occur at various points in the service cycle:

 Pre-service training reaches providers prior to active service provision. For example, nutritional care and support can be incorporated in the training provided at nursing and medical schools or in the training of counsellor candidates.

**Table 5: Possible Capacity Gaps** 

Possible Capacity Gaps	Possible Capacity Development
Inadequate (in numbers or skills) manpower to carry out guideline recommendations.  Low staff motivation.	<ul> <li>Appoint particular staff to perform the nutritional care and support activities in the program or institution.</li> <li>Ensure (by training or supervision) that staff possesses the skills needed for quality care and support: facilitation, mobilisation, counselling, nutrition/dietetics.</li> </ul>
	<ul> <li>If these skills are not available among key service providers or other institutions interacting with PLWHA, advocate for national or sub-national training of targeted service providers in the content of the guidelines.</li> <li>Refer clients to quality nutritional care and support</li> </ul>
	services.
Lack of access to skilled manpower by PLWHA, due	Use community-based organisations and community resources.
to stigma, to lack of knowledge about where to find assistance, to sparse presence of services, or to poor physical access.	Improve the basic skills of community-based resource- persons (or community development committees) to provide appropriate nutritional care and support to PLWHA.
poor physical access.	• Increase awareness about nutritional care and support services and how to access them.
Poor availability of supplies needed for quality care and support (e.g., vitamin/micro- nutrient supplements, IEC	Include nutrition supplies and information packets with other existing service delivery kits and mechanisms.     Establish linkages between nutrition supplies and other materials.
materials, food supplements, counselling cards, etc.).	Retrain providers in logistics management and support.
counselling cards, etc.).	Advocate for increased supply levels and funding for them.
Lack of space or safe outlets for counselling and support of PLWHA.	Given the fear of stigma, privacy is key for any individual nutritional counselling. Creation of space for private counselling is paramount.
Insufficient recognition of nutrition as a key intervention in the care and	Advocate with leaders, managers, and supervisors to appreciate the role of nutrition in care and support of PLWHA.
support of PLWHA.	Generate leadership and support to provide nutritional care and support within different institutions and programs.
Insufficient capacity to plan	In-service, on-site training.
for integrated services.	Facilitative supervision.

- *In-service* training incorporates new knowledge, skills, and approaches to enhance and broaden ongoing activities. For example, VCT counsellors or ANC counsellors can be trained in key recommendations from the guidelines and in processes to support clients to improve nutritional care and support.
- Refresher training reviews previously imparted information or updates service providers in new information about a previously covered topic. For example, to ensure retention and application of nutritional care information, refresher training can be given to counsellors periodically following initial training. This can also include new recommendations based on recent findings and experience.

Training can target a variety of program and service personnel, and different types of training are required for different types of staff. For example:

• Program designers may require training in how to plan services and interventions to include nutritional care and support, e.g., through involvement of nutritional specialists, provision of opportunities for discussion on diets, and mechanisms to minimise stigma, such as private spaces for counselling.

• Service providers and

#### **Innovative methods of training**

- On-the-job training
- Self-paced learning
- Distance learning
- Use of technology-assisted learning (CD-ROMs, internet)
- Nutrition clubs
- Coaching
- **Demonstrations**
- counsellors may require training in the specific content of the guidelines' key messages and recommendations, how to communicate them, and how to support clients. In some situations, different types of service providers may require training on different specific approaches. For example, training of
  - VCT counsellors may have a different emphasis than that for home-based care providers, though the main content will likely remain the same.
- Program and health care managers may require training in the main content of the guidelines, in how to support and manage effective delivery of these messages, and how to orient services for nutritional care and support.
- Staff responsible for *monitoring and evaluation* may require training in how to measure the progress and outcomes of nutritional care and support and in how to use this information (see Chapter 4).

The results of training are strongest when training occurs hand-in-hand with a supervision and support system to improve performance and ensure quality and follow-up.

# 3. Communicate guideline messages to improve nutritional care and support

<u>Purpose</u>: To plan and implement communication of the guidelines' messages through various channels using appropriate communication methods, mechanisms, and materials.

To communicate effectively, the ministries, institutions and organisations using the guidelines, possibly in co-ordination with the TWG, should work with communication specialists to:

- Identify and characterise target groups, and set behaviour change goals for each group.
- Identify and reformulate messages from the guidelines to be communicated.
- Design a strategy to communicate messages to different target groups.
- Identify communication channels.
- Develop communication materials.
- Carry out communication of the guideline messages.

It is not intended that the TWG perform all of the above actions. The team can provide guidance and offer ideas and, in some cases, co-ordination. But it may not be efficient for all of the tasks described in this section to be performed centrally by the TWG. Individual sectors, sub-regions, or programs may implement these activities separately, especially material development and communication. This will help ensure that communication materials and methods are tailored to the different contexts of different sectors and services.

## Identify and characterise target groups and identify behaviour change goals for each group

Sustainable behaviour changes are often most effectively accomplished when communication occurs at multiple levels. To effectively improve the

perceptions, beliefs, and nutrition behaviours of PLWHA, communication approaches are best targeted to specific groups. These groups may include:

- People living with HIV/AIDS and their caregivers;
- Community members, leaders, and support groups;
- Service planners and managers (extension services, VCT, health care, education, etc);
- Service providers (extension workers, doctors/nurses, teachers, trainers, counsellors); and
- Decision-makers (program managers, policy makers, etc).

## What needs to be communicated to the different audiences to improve nutrition habits among PLWHA?

An audience analysis can help provide a clear picture about the reality, perceptions and beliefs of the different groups. Depending on the context, it may be useful to conduct such an analysis separately for individual groups.

### To inform the communication of messages about nutritional care and support, an audience analysis could look at the following questions:

- How do members of the target audience understand the relationship between nutrition and HIV/AIDS?
- What is their role in educating and caring for PLWHA?
- Have they begun changing nutritional behaviours? If so, where are they in the process?
- What is their specific knowledge about healthy eating and nutritional management of HIV-related complications?
- What are their main sources of information and education regarding nutrition and HIV/AIDS?
- What are the barriers to acquiring this information and education?
- What are current nutrition practices in managing HIV/AIDS and related diseases?
- What do they see as the benefits of changing food and nutrition behaviors?
- What pressures or constraints make it difficult to change these behaviors?
- What are their opinions about best methods, channels and timing to convey nutrition and HIV/AIDS messages?

An audience analysis can help to identify the gaps among target audiences in implementing the guidelines and improving nutrition habits for PLWHA. The gaps will lead to communication objectives that relate to:

- Creating awareness of the care and support services that are available;
- Providing detailed knowledge of the issues in nutritional care and support; and
- Teaching improved skills and practices needed to implement nutritional care and support.

### What messages need to be communicated to the audience to support improved nutrition for PLWHA?

The guidelines will provide the content of the messages. Identification of priority areas and behaviours requiring change will define the focus of communication activities. Selection of priority areas and behaviours is based on:

- The extent of the need, i.e., what proportion of the population is affected and how severely;
- The seriousness of the lack of appropriate actions or behaviours in terms of the health and nutrition of PLWHA;
- The interest of the community in addressing the problem. Messages
  - addressing problems that are not perceived as problems by the community will not have much impact, even if the provider knows that these problems exist;
- The feasibility of improving behaviour, taking into consideration barriers to behaviour change such as beliefs or resource limitations of the families or the program; and
- Efficiency of the channels to be used.

### Complementary messages to prevent weight loss

- Malnutrition can contribute to HIV disease progression.
- Try to maintain your weight.
- Get prompt treatment for opportunistic infections.
- After illnesses, eat more to make up for weight loss.

Acceptance of counselling and testing, and of dietary management of HIV may be low because of fear of stigmatisation and rejection by the family and community. Information, education and communication programs on nutrition and HIV/AIDS can help to reduce stigma against HIV-infected people.

Several messages that mutually reinforce each other may be used to achieve a common objective.

#### What characterises "good" messages?

Messages should be clear and creatively developed to make them interesting. Although no single formula exists for message design, below are several useful tips for developing effective messages.

- Keep messages short and simple; include a few key ideas only.
- Give reliable information and as complete information as possible based on existing science-based knowledge.
- Recommend precise behaviour change.
- Show the relation between the nutritional problem and the recommended behaviour.
- Use analogies with things and actions that the audience is familiar with.
- Make use of a slogan or a theme.
- Repeat the idea many times.
- Ensure the message is presented by a credible source.
- Present facts in a direct manner.
- Make use of positive expressions, not negative ones.
- Use examples that are feasible, familiar and resonate with the target audience.

For some messages, the same communication channels and support materials can be used for different audiences.

#### Establish channels to communicate messages

Different groups may be best reached through different specific channels. A communications expert can help the team identify the most appropriate channels to communicate the various messages to target audiences. Much can also be learned from looking at the experience of what has been successful in the past to convey messages to particular groups.

No communication channel is ideal for all target audiences or at all times. Each channel has limitations. For instance, hand posters, brochures and T-shirts can ensure long-term exposure to the message. But the effectiveness of print media is constrained by limited literacy and circulation.

Choose channels with proven effectiveness at reaching the target audience. A multimedia strategy involves an organised use of several channels of communication. Different media reinforce each other. The mix should be based on what is most effective for particular target groups and particular issues. For instance, this may require a combination of interpersonal communication and mass media communication.

Messages on specific issues must be perceived to be consistent and harmonised with other messages communicated through different channels. Some examples of different channels are given in Table 6.

**Table 6: Channels for communicating messages** 

TARGET AUDIENCE AND AIM	SUGGESTED CHANNELS		
Communication to groups, e.g., in health facilities, in communities, at schools (also known as nutrition/health education)	<ul> <li>Group meetings</li> <li>The use of visual and audio-visual supports</li> <li>Participatory methodologies to ensure that "discussions" do not become "monologues"</li> <li>Education sessions</li> </ul>		
Providing information to a wide spectrum of groups of people or to the general public. Useful for awareness and knowledge, but less so for skills.	<ul> <li>Mass media including radio, television and video</li> <li>Public ambassadorship by role models</li> <li>Public display of information</li> <li>Products: T-shirts, caps, posters, etc.</li> <li>Music groups</li> <li>Theatre or art groups</li> <li>Private sector campaigns</li> </ul>		
Providing information to interest groups	<ul> <li>Individual testimonials</li> <li>Peer group discussions</li> <li>Nutrition-HIV ambassadors</li> <li>Pamphlets (among the literate)</li> </ul>		
Providing information to individual PLWHA and/or caregivers	<ul> <li>Counselling sessions</li> <li>IEC activities</li> <li>Peer group discussions and peer testimonials</li> <li>Agricultural extension, education, and other contact opportunities by credible agents</li> <li>Private sector activities</li> </ul>		
Discussion and problem solving with PLWHA	<ul><li>Individual (or group) counselling</li><li>Support group discussions</li><li>Participatory discussions</li></ul>		

As far as possible, members of the target audience should participate and engage in the communication process and not be mere receivers of information. This will help inform and strengthen the communication process and also generate greater ownership of the messages on the part of the target audience.

Peer communication through peer groups or individual contact is a very effective channel because the testimonial of individual PLWHA or caregivers about the benefits of nutritional care and support can increase credibility and be a strong source of behaviour change for others.

#### Develop materials to communicate the messages

Many communication channels involve development of materials. Table 7 includes examples of such materials.

**Table 7:** Types of Communication Materials

• Brochures	Training manuals
• Pamphlets	<ul> <li>Handbooks</li> </ul>
• Posters	<ul> <li>Job aids</li> </ul>
• Flip charts	• Library
Radio spots	• Leaflets
• TV spots	<ul> <li>Booklets</li> </ul>
Newspaper articles	• Issue briefs

Suggested by country teams at the regional workshop on national guideline development in Jinja, Uganda, November 2001.

Different materials may be needed to communicate the guideline content to different target audiences. Table 8 presents an example of how to organise and plan support materials based on different target audiences. The materials given in this table are illustrative; teams should identify the specific materials required based on the target audiences and the communication channels in their countries.

Table 8: Support materials to communicate guidelines recommendations to various target audience

Target audience	Booklets	Training curricula, Fact sheets, Short manual	Issue briefs	Radio spots, News- paper articles	Posters, Pamphlets, Products,	Job aids (counselling card, flip chart)
Agricultural exten. workers	X	X		X	X	
Health workers, counsellors	X	X		X	X	X
Educators	X	X	X	X		
Manufacturers			X	X		
PLWHA				X	X	X
Network groups	X	X	X	X	X	X
Policy Makers	X	X	X	X		
General public				X	X	

Adapted from the Uganda TWG, Nov. 2001

#### Material development

Developing communication materials may require collaboration between people not used to working together; program staff, communication experts, technical experts, nutritionists, graphic artists, and printers may have different ideas about the production of materials. Inclusive facilitation of this process may therefore be necessary.

Pre-testing of materials is often a neglected process, but it offers valuable feedback about the effectiveness of messages and materials. Pre-testing can lead to immediate improvements in the materials and messages. Pre-testing may focus on the following:

- Attention Do the message and the presentation catch and maintain one's attention?
- *Comprehension* Is the message clearly understood? Are the graphics easily grasped?
- *Relevance* Are the messages of concern to the audience? Do recommendations use examples and pictures familiar to the audience?
- *Credibility* Are the guidelines and information sources technically well established?

- *Acceptability* Are the messages culturally sensitive?
- Feasibility Are the recommendations feasible for the target audience?

The teams responsible for this process should ensure that a sufficient number of materials are produced and reach target groups. Estimation of the numbers of required materials and distribution planning may require consultation with key stakeholders, program implementers, and users.

# Chapter 4. Monitoring and Evaluation (M&E)

#### Introduction

In the process of developing and applying national guidelines, it is critical to monitor and evaluate progress and outcomes periodically. Effective monitoring and evaluation:

- Encourages accountability and commitment to timeframes;
- Helps those managing the process to identify and address areas for improvement;
- Demonstrates the level of results achieved; and
- Enables critical information to be shared with key stakeholders.

Nutritional care and support for PLWHA is a relatively new intervention with new information and experiences continually emerging. The development and use of national guidelines is also a new process for many countries. Therefore, M&E is particularly important in order to understand emerging results and improve practices.

For complex multi-stakeholder processes such as national guideline development and application, monitoring can help to maintain accountability and efficiency. For example, monitoring the dissemination of guidelines helps to ensure that they reach the intended users and helps provide information to improve dissemination efforts in the future.

Monitoring and evaluation can also inform the revision and redevelopment of guidelines by providing information about the relative effectiveness of different aspects of the guidelines and helping to identify gaps and further needs.

As with other steps in the guideline development process, each country must develop an M&E plan that suits its particular context and objectives. This chapter lays out some key steps and considerations to assist in developing and implementing M&E for national guidelines.

#### 1. Plan for monitoring and evaluation

Developing an M&E plan early in the process of guideline development helps stakeholders to identify the main results they aim to achieve and helps them plan effective activities. Designing an M&E system provides a useful framework in which to think through and organise the objectives and steps of national guideline development. Therefore, while the primary purpose of M&E planning is to establish effective M&E mechanisms, this planning can also improve understanding of the guideline development process.

The core team overseeing the development and application of national guidelines needs to plan key components of the monitoring and evaluation process. In order to do so, the team may want to consider the following questions:

- Which main stages and objectives of the process should be assessed? For example, it may be decided that assessing the dissemination of the guidelines is important, but that assessing the impact on PLWHA of the use of the guidelines is beyond the team's manageable interest.
- Who will be responsible for monitoring and evaluating the various stages in the process? Clear responsibility should be assigned for each stage being assessed.
- How will key information be reported to stakeholders?
- What mechanisms will be used to ensure follow-up based on the information received?
- What, if any, aspects of M&E need to be included in the guidelines document itself? For example, information on assessing behaviour change among beneficiaries may be useful.

#### Learn from South Africa's Experience

In 2001, South Africa published South African National Guidelines on Nutrition for People Living with TB, HIV/AIDS and Other Chronic Debilitating Conditions. At a regional workshop in May 2002, a member of the South African team shared a lesson with other countries. She said that the biggest mistake they had made in South Africa was that they did not conduct any monitoring or evaluation. As a result, they do not have strong information about how the guidelines are used, what improvements are needed, etc. She suggested that other countries learn from South Africa's experience and monitor and evaluate throughout the process of national guideline development and application.

Depending on their contexts and needs, different countries may focus their M&E efforts on different areas. For example, a country in which official endorsement and adoption of the national guidelines by multiple ministries is a critical step for their use may choose to include strong monitoring of national-level advocacy efforts and results. A country with heavily decentralised programs and systems may focus on measuring district-wide dissemination and use of the guidelines.

Most countries developing national guidelines will measure certain basic components, such as completion of key steps in guideline development, and the extent of dissemination and use. But how and to what extent these areas are measured will vary between countries. The next section describes a suggested process to determine which specific areas are most valuable to measure and how to measure them.

#### 2. Develop a monitoring and evaluation system

To develop a specific monitoring and evaluation system, one can follow a stepby-step process such as the one described below. Since different stages in the development and application process have different sets of objectives and activities, it may be best to complete these steps separately for the different stages to be monitored.

1. *Identify objectives*. For example, an objective of application of national guidelines may be to incorporate knowledge and recommendations from the guidelines into programs, activities, and communication methods for those working with PLWHA.

#### How Different Nutrition and HIV Stakeholders Use Monitoring & Evaluation Information

#### CLIENTS (PLWHA and caregivers)

• To reinforce the benefits of nutritional care and support. To motivate participation and behavior change.

#### IMPLEMENTERS (counselors, field agents)

 To identify what is working well and what is not in order to inform adjustments and improvements. To reinforce the value of nutritional care and support efforts.

DESIGNERS and MANAGERS (a. those managing guideline development/application; b. program designers and managers)

• To guide planning and supervision. To enable improvements in ongoing activities. To inform future nutritional care and support activities. To report on progress and results.

POTENTIAL NEW STAKEHOLDERS (a. in-country stakeholders not presently involved; b. those in other countries who may begin guideline development and nutritional care interventions)

 To encourage involvement in, and initiation of, nutritional care and support efforts and activities.

#### **DONORS**

- To understand progress and results. To inform future resource allocations.
  - 2. *Identify the process and activities* used to achieve these objectives. For example, for application, this may include trainings, development and use of educational materials, etc.
  - 3. Determine how progress can be measured toward these objectives, and how outcomes and impact can be measured. This involves *defining indicators*. For example, one way to measure application of the guidelines is to measure counsellors' knowledge of key recommendations from the guidelines. Indicators should cover all the critical areas that the team decides require assessment. Defining indicators is a critical part of the M&E process because indicators determine the type of information collected. More information on indicators is provided later in the chapter.
  - 4. Determine the level of change expected to be achieved for each indicator and a timetable for achieving this change. This involves *identifying targets* for each indicator. For some indicators, there may be multiple targets to be achieved at different times, such as a certain percentage of counsellors with knowledge of key recommendations after six months, and a greater percentage after one year.

- 5. *Plan information collection* once the indicators and targets have been defined. Answering the following questions can help to form an information collection plan:
  - What information is needed to measure the indicators?
  - Who will collect the information?
  - What process will be used for collecting the information? What tools are needed?
  - What is the timeframe for information collection?
  - Who will analyse the data and how?
  - What information is needed by whom? (For example, a donor may need somewhat different information than the team organising guideline development or than a counsellor does.)
  - How will the information be reported to those who need it?

#### Monitoring vs. Evaluation

**Monitoring** involves regular measurement of progress in key processes and outputs. Monitoring usually involves periodic measurement and is often conducted by the institutions involved in managing and implementing activities.

*Example:* Measuring the number of institutions, programs, ministries, agencies, and companies receiving copies of the guidelines serves to monitor the dissemination process.

**Evaluation** involves assessing the impact of activities and the extent to which main objectives have been achieved. Evaluation may involve less frequent measurement and may be conducted by outside parties, though not necessarily.

Examples: Measuring the number of programs incorporating key messages from national guidelines could be an evaluation of guideline application. Measuring the health status of PLWHA before and after nutritional care interventions is an evaluation of the interventions' impact.

Using this process, those responsible for M&E can develop a specific M&E plan that includes indicators, targets, and information collection and reporting methods for each part of the process being monitored. Table 9 gives an example of an excerpt from such a plan.

Depending on the level of detail desired, such a plan can also include reporting methods, assumptions, indicator units, or other information.

It is often valuable to supplement quantitative M&E with qualitative approaches. For example, forms to provide feedback can be included with guidelines when they are distributed, with a request that users complete and

send these forms to the co-ordinating body. Other methods to collect qualitative feedback from guideline users, such as interviews and focus group discussions, can also be considered.

Table 9: Example Excerpt of a M&E Plan

Objective	Indicator	Targets	Data Collection Method	Responsible Dept/Person
	Percentage of MOH ANC service providers & health/nutrition counsellors trained in guideline recommendations.	Month 12 – 50%  Month 18 – 80%	Analysis of training curricula and training records. Also sampling of service providers.	National AIDS Control Program (NACP)
Incorporation of Guideline Rec-ommendations into Programs and Services	Percentage of counsellors at MOH and NGO PLWHA programs with knowledge of three key guideline recommendations.	Month 12 – 40%  Month 18 – 75%	Sampling of service providers. Identification of key recommendations.	Program implementers and NACP.
	Percentage of home-based care programs providing nutritional care and support.	Month12 – 60%  Month 18 – 85%	Sampling of home-based care activities. Interviews with recipients.	Home-based care program managers and supervisors, w/oversight by NACP.

#### Levels of guideline development and application

As described earlier in this handbook, development and application of national guidelines involve a number of separate stages or levels. For the purpose of monitoring and evaluation, it may be helpful to look at each level separately since each involves separate objectives, activities, and results and therefore requires different M&E. One way to organise the entire process for the purpose of M&E planning is to use the following five general levels:

- 1. Development of national guidelines
- 2. Dissemination of guidelines and development of materials, curricula, etc. based on guidelines

- 3. Incorporation and application of guideline information and recommendations in interventions, programs, services, and other delivery points
- 4. Behaviour change by PLWHA
- 5. Impact on health, nutrition and well-being of PLWHA

Each level will involve different indicators, targets, and measurement processes because the objectives and process are different for each level. As part of the process of guideline development, it will generally be useful to monitor and evaluate levels 1 and 2 (guideline development and dissemination) and possibly parts of level 3 (application). Levels 4 and 5 (behaviour change and impact on PLWHA) and parts of level 3 (application) are more likely to be monitored by specific programs or services using the guidelines and not by those developing and disseminating them.

#### 3. Indicator selection

Selection of indicators is a key step in designing M&E because indicators define what is measured and thereby drive the M&E process. Defining effective indicators requires identifying the measurable changes activities aim to achieve and articulating how these changes can be feasibly measured.

For example, if use of the guidelines is expected to provide antenatal counsellors with knowledge about recommended dietary practices for HIV-positive pregnant women, then an indicator could be defined as the percent of ANC counsellors with knowledge of these recommendations. This could be measured by checking the knowledge of counsellors from a sample of programs receiving the guidelines. (Note that measurement at this level may be better suited to the individual implementing programs than to the team developing the guidelines.)

Generally, measurement of percentages provides more useful information than measurement of absolute numbers. For example, knowing the percentage of VCT programs integrating nutritional care and support is probably more informative than knowing the number of programs doing so. (If information about the total number of VCT programs is difficult to acquire, a representative sample can be taken.)

Table 10 provides examples of possible indicators for each of the five stages. These indicators are meant to be illustrative, not comprehensive; to identify appropriate indicators for a specific situation, one should examine the specific objectives, activities, and environment, as described above.

**Table 10: Example Indicators** 

Level	Example Indicators
Development of national	Percentage/number of stakeholders involved in the process (attending meetings, reviewing drafts, contributing information, etc.).
guidelines	Percentage/number of different types/sectors of stakeholders involved.
	• Completion of key steps. Identify key steps such as materials review, stakeholder meetings, drafting of guidelines, review, advocacy activities, etc., and monitor their completion. The target may include a timetable for completion.
	Output indicator such as production of guidelines.
Dissemination of guidelines and development of materials based on guidelines	Percentage/number of institutions, programs, ministries, agencies, companies to which guidelines are provided.
	Percentage/number of different sectors to which guidelines are provided (e.g., health, agriculture, education, tourism, private sector, etc.).
	Percentage/number of key ministries endorsing or adopting the guidelines.
	Number of distinct materials, curricula, etc. developed using guidelines.
	• Number of different types of materials developed using the guidelines (e.g., counselling cards vs. radio messages vs. inclusion in teaching curriculum vs. posters vs. brochures vs. module in nurse training, etc.).
and application of guideline information and recommenda- tions into	Most of these indicators can be disaggregated (broken down) by type of program, intervention or service if that information is useful.
	• Accurate inclusion of key information and recommendations from guidelines in programs, services or other activities. One way to define this indicator is "the percentage (or number) of programs/services that include key recommendations from the guidelines". <sup>2</sup>
programs, services, and other delivery	Percentage/number of counsellors, service providers, etc. trained in information and recommendations from the guidelines.
points	Percentage/number of VCT programs that include nutritional care and support.

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<sup>&</sup>lt;sup>2</sup> This can be measured by identifying a few specific, key recommendations from the guidelines and then looking at how many programs/services include them. (To avoid having to measure all programs, a random sample of those institutions receiving the guidelines could be used.)

Level	Example Indicators		
	<ul> <li>Percentage/number of private sector companies with nutritional care and support activities.</li> </ul>		
	<ul> <li>Percentage/number of home-based care programs that include nutritional care and support.</li> </ul>		
	• Percentage/number of hospitals offering nutritional care and support.		
	• Knowledge levels of key implementers (counsellors, etc.) in guideline information. The indicator could be defined as "the percentage of key implementers with knowledge of three key recommendations from the guidelines". <sup>3</sup>		
	• Coverage: Approximate number of beneficiaries receiving inputs from programs, services, etc. that incorporate guideline recommendations.		
	• Knowledge levels of the target audience (PLWHA, primary caregivers). This could be defined as "the percentage of beneficiaries from programs/services receiving the guidelines who know three key recommendations from the guidelines". <sup>4</sup>		
	• Effectiveness of communication of guideline recommendations. This can be defined for example as "percentage of counsellors scoring higher than 75 percent on a nutrition counselling checklist". <sup>5</sup>		
Behaviour	• Frequency of eating		
change by PLWHA	• Dietary diversity: number of different types of foods consumed		
ILWIIA	Protein intake		
	Energy intake		
	<ul> <li>Practice of recommended dietary responses to symptoms (nausea, diarrhoea, thrush, etc.)</li> </ul>		
	Timing of meals to manage food-drug interactions		
Impact on health,	Weight or weight-for-height		
nutrition, well- being of	• Body-mass index (BMI)		
PLWHA <sup>6</sup>	Physical activity		
	Ability to perform basic work activities		
	<ul> <li>Frequency and severity of opportunistic infections</li> </ul>		
	• Frequency and severity of symptoms		
	Ability to eat		

<sup>&</sup>lt;sup>3</sup> One way to measure this is to identify three key recommendations or points of information and then check the knowledge of a sample of implementers.

<sup>&</sup>lt;sup>4</sup> Again, this could be measured by identifying key recommendations and checking the knowledge of a sample of beneficiaries.

This can be used for counselling situations and may involve using a counsellor checklist to assess the

communication of nutritional care information.

<sup>&</sup>lt;sup>6</sup> While these are all indicators that nutritional care and support is expected to improve, using them to evaluate the impact of nutritional interventions can be problematic because a) there are many confounding factors that can affect these indicators more strongly than nutrition does, and b) over the long run the health and nutritional

## 4. Monitoring and evaluation information within national guidelines

The team designing national guidelines needs to consider what, if any, information on monitoring and evaluation to include in the guidelines themselves. This will depend on the expected role and users of the guidelines. Possibly, a summary of the different levels that can be assessed, such as levels 1-5 above, may be useful. Laying out these levels helps to show what areas can be monitored and also helps provide guideline users with an organising framework in which to understand the role of the guidelines and how they can be used.

Since guideline users are likely to be working at levels 3, 4, and 5, it may be useful for guidelines to briefly describe the type of M&E that can be applied at these levels. Depending on the amount of detail desired, suggested indicators and measurement processes could also be included.

Irrespective of what is included in the guideline text, it is critical for the team responsible for guideline development and application to identify which parts of the process should be monitored or evaluated and to develop and implement a feasible M&E plan accordingly. Effective monitoring and evaluation leads to a more efficient process and provides information to improve and demonstrate results.

### **Resource Materials**

#### **Documents**

HIV/AIDS: A Guide for Nutrition, Care and Support. Food and Nutrition Technical Assistance Project, Academy for Educational Development, Washington DC, 2001.

Lamptey Peter, Paul Zeitz and Carol Larivee. *Strategies for an Expanded and Comprehensive Response to a National HIV/AIDS Pandemic: A Handbook for Designing and Implementing HIV/AIDS Programs*. Family Health International and USAID, 2001.

Living Well with HIV/AIDS: Nutritional Care and Support for People Living with HIV/AIDS. Food and Agriculture Organization and World Health Organization, 2002.

*Manual of Clinical Dietetics*. American Dietetic Association and Dieticians of Canada. Sixth edition, 2000.

*Nutrition Essentials: A Guide for Health Managers.* WHO/BASICS/UNICEF, 1999.

Piwoz, Ellen G. and Elizabeth A. Preble. *HIV/AIDS and Nutrition: A Review of the Literature and Recommendations for Nutritional Care and Support for Sub-Saharan Africa*. Support for Analysis and Research in Africa (SARA) Project. Washington DC, 2000.

Pronsky, Zaneta, Sharon Ann Meyer and Cade Fields-Gardern. *HIV Medications Food Interactions*, Second Edition, 2001.

South African National Guidelines on Nutrition for People Living with TB, HIV/AIDS and Other Chronic Debilitating Conditions. Ministry of Health, South Africa, 2001.

#### Other Resources

AIDS Nutrition Services Alliance website, www.aidsnutrition.org

Care of Women with HIV Living in Limited-Resource Settings. JHPIEGO, ReproLearn Tutorials, 2002.

(Available on CD-ROM or at www.reproline.jhu.edu/video/hiv/tutorials/index.htm)

*CDCynergy 2001: Your Guide to Effective Health Communication.* Centers for Disease Control and Prevention, 2001.

(Available on CD-ROM. E-mail: Cdcynergy@cdc.gov. Website: www.cdc.gov/cdcynergy.)

World Health Organization website, www.who.int

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Andrien, Michel. Social Communication in Nutrition: A Methodology for Intervention. Food and Agriculture Organization, 1994.

Chopra, Mickey, David McCoy, David Sanders and Ellen Piwoz. *How to Conduct a Rapid Nutrition Situation Assessment*. Health Systems Trust, 2000.

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Sanghvi, Tina and John Murray. *Improving Child Health through Nutrition: The Nutrition Minimum Package*. BASICS Project USAID, 1997.

South African National Guidelines on Nutrition for People Living with TB, HIV/AIDS and Other Chronic Debilitating Conditions. Ministry of Health, South Africa, 2001.

UNICEF, UNAIDS and WHO. HIV and Infant Feeding: A Guide for Care Managers and Supervisors. 1998

UNICEF, UNAIDS and WHO. HIV and Infant Feeding: Guidelines for Decision Makers. 1998.

WHO, BASICS and UNICEF. Nutrition Essential: A Guide for Health Managers. 1999.

WHO. IMCI Adaptation Guide. WHO and UNICEF, 2001.